

Are you aware about the fact that you should be consented by your optometrist on the referral form? Yes/No (46% / 54%)

Did your optometrist explain to you about the consent statement mentioned on the GOS 18 form? Yes/No (40% / 60%)

Would you like the ophthalmologist to make available your medical information to your optometrist/ophthalmic medical practitioner? Yes/No (85% / 15%)

Conclusion

Only a few GOS 18 forms contained patients' written consent for information to be sent back to the referring optometrist.

Fifteen per cent of the patients surveyed, said they did not wish information to be shared with their optometrists. Therefore we should be careful about sending back information to optometrists where signatory consent has not been given.

Optometrists need to be aware of this potential issue. In the light of the increasingly close relationship between optometrists and ophthalmologists (especially where they share care for glaucoma and postoperative cataract patients) it is important for the optometrist that consent is given if feedback is required.

Discussion

A good doctor-patient relationship can be defined by the three Cs: (i) Confidentiality, (ii) Consent, and (iii) Competence. If any of these three components are missing the doctor-patient relationship could be damaged and the flow of communication in both directions inhibited.

A promise on the part of the doctor to maintain patient confidentiality is central if patients are to be allowed to speak freely. If information is shared without the patient's consent then the faith of the patient in the doctor may be forfeited.

Consent is an integral part of the GOS 18 referral form but our study shows that it is taken for granted and is not handled in accordance with guidelines set out in medical law.

Y Khan

SHO Ophthalmology, Ashford Hospital, London Road, Middlesex, TW15 3AA, UK; yasir1399@hotmail.com

R J Stirling

Darlington Memorial Hospital, Hollyhurst Road, Darlington, DL3 6HX, UK

Tuskegee syphilis study, or, to give it its full title, the US Public Health Service's *Tuskegee Study of Untreated Syphilis in the Negro Male*. This study, conducted from 1932 to 1972, on black (African American) males in Tuskegee, Alabama, has, with complete justification, become the paradigm of moral depravity in the field of biomedical research. Virtually every rule of good, ethical research was broken during this "research" over a period of 40 years, down to denying participants even the knowledge, let alone the option, of a remedy when it became available.

In recent years, the Tuskegee syphilis study has received renewed public attention, for two reasons. First, in 1996, 24 years after the cessation of the study, President Clinton provided a formal federal apology, saying to the survivors that "[w]e can look at you in the eye and finally say on behalf of the American people, what the United States government did was shameful, and I am sorry". With this apology, Clinton not only accepted moral responsibility—something not easily done by governments in the affairs of state, domestic or foreign—but also contributed to addressing African Americans' distrust of health care and biomedical research, a distrust fuelled by the legacy of Tuskegee.

Second, echoes of Tuskegee have been heard in the ongoing debate about the ethics of biomedical research financed or conducted in the developing world by government agencies and companies from the developed world, particularly in regard to HIV/AIDS. Such research raises ethical questions, relating to key issues such as exploitation and justice, informed consent, and duties of beneficence. David J Rothman puts the underlying concern as follows: "Until the 1990s American medical researchers performed most of their experiments on other Americans—frequently choosing subjects who were poor and vulnerable. Now, however, they are increasingly likely to conduct their investigations in third world countries on subjects who are even poorer and more vulnerable".¹ HIV/AIDS and escaping the possibility of financial and regulatory burdens are cited as reasons for this shift. The ethics of Tuskegee has been internationalised.

For this reason, but also for several others, Susan M Reverby's edited volume, *Tuskegee's Truths: Rethinking the Tuskegee Syphilis Study*, is a welcome, and indeed magisterial, addition to the Tuskegee literature. In a volume of 630 pages, the editor has put together a resource containing virtually everything one would wish to know about the Tuskegee study—information, transcripts of historical documents, reflections, moral lessons. In a single volume one gets a panorama, as well as detailed mapping, of this sorry saga in US biomedical ethics.

The book begins with an Overview (part I) and Contemporary background (part II). This is followed by an extensive section, Documenting the issues (part III), which includes material such as the testimony by four survivors from the United States Senate hearings on human experimentation, in 1973. Part IV focuses on The Question of treatment, while part V is an Historical reconsideration. The much debated role played by nurse Rivers is rethought in part VI. The Legacy of Tuskegee is considered in part VII, while Key actors rethink the study in part VIII. Part IX, Imagining the Tuskegee syphilis study, moves into the realm of fiction and poetry, with, among others, selections from the play, *Miss Evers' Boys*. The final part, part X, Apology and beyond, contains such significant recent

documents as President Clinton's apology speech and Marcia Angell's 1997 editorial in the *New England Journal of Medicine*.

I strongly recommend this important volume for anyone interested in the ethics of biomedical research. By rethinking the past we may understand the dangers inherent in such research. From the perspective of the developing world, we need to be armed with the knowledge to help us prevent history from repeating itself, at least in this respect.

W A Landman

Reference

- 1 Rothman DJ. The shame of medical research. *The New York Review of Books* 2000;XLVII:60–4.

Genes, Women, Equality

M B Mahowald. Oxford University Press, 2000, US\$39.95 (hb), pp 314. ISBN 0-19-512110-4

Far too often it is still assumed that if feminist bioethics has any role to play, its contribution lies purely in reproductive ethics. Mary Mahowald's *Genes, Women, Equality* should dispel that delusion once and for all, along with a second illusion: that the new genetics is gender-neutral.

Mahowald is not a bioethical Luddite: she is not concerned to attack the new genetics, but to make good the failure of bioethicists and scientists to explore the differential impact of the new genetics on women. Specific implications for women of advances in genetics in different fields form the bulk of the book, with chapters on genetic counselling; genetics research; allocation of genetic services; culture and sex selection; misattributed paternity and cystic fibrosis; sickle cell disease and carrier testing; breast cancer susceptibility testing; preimplantation genetic diagnosis and abortion; genomic alternation; genetically linked alcoholism, employment and insurance testing, and human cloning.

This last chapter is a prime example of the need for Mahowald's sort of analysis: how often is it recognised that even therapeutic cloning and stem cell research, such as was recently approved by the UK parliament, affect women differently from men? The obvious reason is that large numbers of enucleated eggs will be required, and that enucleated eggs come from women, taken in a painful and difficult procedure. But as Mahowald mildly notes, so far as the further step of human cloning goes: "Interestingly, while some bioethicists expressed concerns about the impact of human cloning on cloned individuals, none, to my knowledge, indicated that there were gender differences to worry about as well" (pages 281–2).

These practical chapters show Mahowald's clinical knowledge to good advantage (although a philosopher, she is professor in the college, the Department of Obstetrics and Gynecology, the Committee on Genetics and the MacLean Center for Clinical Medical Ethics at the University of Chicago.) Her analysis is particularly clear here, and in other "repro-genetics" chapters, especially in the distinction she draws between genetic, gestational, and lactational motherhood. She rightly draws our attention to a fourth form of motherhood which can also now occur: the provision of enucleated eggs, into which another set of genes is inserted. Which of these is "real" motherhood?

BOOK REVIEWS



Tuskegee's Truths: Rethinking the Tuskegee Syphilis Study

Edited by S M Reverby. University of North Carolina Press, 2000, £52.50 (hc), £19.95 (sc), pp 630. ISBN 0-8078-4852-2

No one interested in the ethics of biomedical research will have failed to hear about the

There are also a series of “mid-level theory” chapters, such as that on Disabilities, feminism and caregiving, which is informed by the split in feminist thought between disability rights feminists such as Adrienne Asch, who distrust genetic screening and correlated abortion on the grounds that they discriminate against the disabled, and other feminists such as Christine Overall,¹ or Mahowald herself, who distinguish between the legitimate abortion of fetuses with disabilities and advocacy for disabled people (and their carers, usually women). The analysis in both the “specific issues” and the “mid-level” chapters will be of enormous use to both practitioners and academics.

Mahowald also attempts to provide a normative foundation for the two less theoretical sorts of chapters, particularly in her chapter 4, Gender justice in genetics. Here she employs what she terms a feminist standpoint approach or egalitarian feminist model, which directs our attention towards power imbalances. Where inequalities result from rectifiable social power imbalances rather than unalterable and value-neutral differences, the standpoint of the less powerful group should be privileged over that of the more powerful, in this model. “Some differences entail inequalities; others are merely associated with them” (page 74). Inequalities which persist by mere association, such as the continued association of women with caregiving, are more easily rectifiable; biological differences, such as the fact that it is women who give birth, are harder to remedy, but we should try to minimise their impact. Certainly we should not allow necessary biological inequality to become an excuse for avoidable social inequality, but that is what some aspects of the new genetics risk doing.

The feminist standpoint model is frequently contrasted with a conservative libertarian model, as the theoretical overview which has so far dominated in the new genetics. While I agree with this part of Mahowald's analysis, I am less convinced that the liberal feminist model is always wrong, even though I do not count myself a liberal feminist. There is a certain risk of demonisation of the liberal feminist view, which Mahowald does not always avoid; it is not the same as libertarianism. On the whole, however, this is a vital book for anyone interested in the new genetics—yes, even for those who don't actually think they are also interested in feminism.

D Dickenson

Reference

- 1 Overall C. New reproductive technologies and practices: benefits or liabilities for children? In: Dickenson D, ed. *Ethical issues in maternal-fetal medicine*. Cambridge: Cambridge University Press, 2002.

On Dying Well: An Anglican Contribution to the Debate on Euthanasia

Board for Social Responsibility of the Church of England, Church House Publishing, 2000, £4.95, 94 pages, 0 7151 6587 9

For any reader interested in euthanasia, *On Dying Well* gives an accessible yet detailed account of the Church of England's view on the subject. First published in 1975, this short report is the product of the Church's Board for Social Responsibility, which brought together

theologians, philosophers, lawyers, and medical professionals to form a working party with the remit of examining euthanasia. The second edition of *On Dying Well* leaves most of the original working party report findings unaltered, but adds a new introduction by Professor Stuart Horner, chairman of the British Medical Association's ethics committee from 1989 to 1997. Other changes to the first edition are a redrafted chapter on the legal questions surrounding euthanasia in light of new cases pertinent to the debate and additional reflections on the report's medical content. Also included is an updated bibliography, listing publications produced after 1975 and, in appendix form, the 1993 Joint Submission to the House of Lords Select Committee on Medical Ethics made by the House of Bishops of the Church of England and the Roman Catholic Bishops' Conference of England and Wales.

On Dying Well is a report of broad-ranging scope which, not surprisingly, robustly rejects the legalisation of voluntary euthanasia. This rejection operates in two ways—marshalling both principled, theologically grounded rhetoric and more practical, medically orientated arguments and clinical case studies. Thus, in his introduction, while acknowledging that most churches “would now approve the language of human rights”, Professor Horner rejects what he terms an “unbridled” notion of autonomy which ignores an “ultimate accountability to God”. Then on a more practical level, he stresses the significant impact that developments in palliative care have had on care of the dying, arguing that in the vast majority of cases “there is almost no reason today for patients with an incurable condition to die in agony and distress”. Lamenting that hospice care is not available to all terminally ill patients, Professor Horner nevertheless maintains that this is no reason to write euthanasia into the statute books. He dismisses arguments that focus on poor standards of terminal care as a justification for legalising euthanasia, adding that it seems “utterly illogical that if doctors are guilty of bad terminal care, society should then award them greater powers to remedy the problem”.

This reference to the distribution of “power” within the doctor-patient relationship goes to the heart of the euthanasia debate, as conceptions of what constitutes “good death” are negotiated and renegotiated against a backdrop of ever-changing medical practice and wider societal values. There are those who do, of course, reject the view that the legalisation of euthanasia represents an allocation of “greater powers” to doctors, but instead view euthanasia as a crucial element in securing personal autonomy and self-determination for the patient. When the Voluntary Euthanasia Society published its 1976 rejoinder to the first edition of *On Dying Well* it concluded that the church's report was “determined, and often distorted by . . . an absolute prior rejection of euthanasia”.

However, the focus of the church's report is largely on the potential implications of *legalising* euthanasia and interestingly, both the theological and the medical chapters of the book concede that there may be “exceptional cases” in which euthanasia is morally permissible. It is argued that such instances, judged by the report to be extremely rare, are best dealt with on a case by case basis rather than by altering the status of the law. The report concludes that the legalisation of euthanasia would have numerous damaging effects, including reducing the incentive to improve provision of care for the dying; placing

patients under pressure to seek an end to their lives, and, ultimately, increasing the risk of non-voluntary euthanasia.

Some readers will be left unsatisfied by this endorsement of the “slippery slope” view of legalising euthanasia. Similarly, not every reader will be satisfied with the conclusion that euthanasia excludes the administration of drugs to relieve pain or distress, even if this does, on occasion, and as the report concedes, carry the risk of shortening life. On this front, the report is vulnerable to the charge that it retreats behind euphemisms—emphasising the proposed “intention” of a doctor solely to relieve pain, but avoiding difficult questions that accompany the acknowledgement that a patient's life may be shortened as a result. Nevertheless, the medical and theological pragmatism of the report stands in contrast to the unbending position that might have been offered. There will be those who, perhaps unable to view the question of euthanasia through the particular religious lens of the Church of England, will share similar anxieties about the repercussions of legalising assisted suicide.

The highly publicised efforts of motor neurone disease patient Diane Pretty to secure her “right to die” have once again stirred the sometimes dormant but ever present debate over euthanasia. The media coverage has brought into focus now well rehearsed positions—where respect for autonomy and individual choice compete with sanctity of life and “slippery slope” arguments. *On Dying Well* reiterates these arguments but also offers new insights and analysis. It is worth noting that in the same week that Diane Pretty's case made the headlines, Dame Cicely Saunders, a contributor to the church's report, was awarded the \$1m Hilton Humanitarian Prize for her hospice work in the care of the dying. The philosophical debate surrounding euthanasia has reached an impasse. The “solution” for now, appears to lie in allowing death with at least some degree of self regulation but without appeals to changes in the law.

L Campbell

Bio Engagement: Making a Christian Difference through Bioethics Today

Edited by N M de S Cameron, S E Daniels, B J White. William B Eerdmans Publishing Company, 2000, £14.99, pp 265 + xiii. ISBN 0-8028-4793-5

This book is concerned with advocating a pro-life stance rather than with detailed discussions of the medical ethics of biotechnology. The essays are written from the particular Christian perspective of conservative evangelicalism and the writers are committed to the verbal inspiration of scripture. It is a book which will be of interest to a certain section of the Christian church. One constraint with this approach is the sense of the discussion taking place “in house”, calling Christians of like mind to defend a pro-life stance on health care. Occasionally writers with contrasting points of view are mentioned but there is no sustained discussion of their arguments. The pervasive advocacy of the pro-life view only occasionally yields to a recognition of the complexity of the issues and the general, unacademic, level of the discussions does not provide any detailed argument and support